

## Ex. 6 Personal Privacy (PP)

January 27, 2020

To all concerned:

This letter goes out to you collectively as a follow-up to my earlier individual contact with some of you (Loretta Haddy, Lora Werner, Paul Mehta, Shelley Moore Capito) regarding a concern I'd had over the unusually high incidence of ALS in our small community as well as MS, and other neurological problems. For those of you who did not previously have contact with me, I feel it is necessary to make you aware as well.

In March 2016, my husband and I were outside doing our yearly maintenance of trimming our Chinese Elm Hedges. We noticed a lot of vehicles coming and going at the home of our neighbors **Ex. 6 Personal Privacy (PP)**. We have been neighbors with them since we moved to this home in 1987. The following day we learned that **Ex. 6 Personal Privacy (PP)** had been diagnosed with ALS. None of us really knew the particulars of the disease. We'd all done the ice bucket challenge in recent years in support of it, but none of us knew anyone who had the disease. In fact, statistically, this disease is reported to strike about 2-5 in 100,000. One odd thing though is the fact that we later learned that another nearby neighbor **Ex. 6 Personal Privacy (PP)** passed from ALS the previous Fall of 2015. **Ex. 6 Personal Privacy (PP)**

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I initially contacted Loretta Haddy, State Epidemiologist of WVDHHR. She and I spoke on the phone one Saturday. I asked about having someone come to our area to see what was going on as this was a clear case of an environmental exposure. We discussed power lines, algae bloom, and a number of other potential sources. At the time we didn't know and were brain-storming potential triggers. My suspicion at the time was Roundup weed killer because my husband had used it and so had our neighbor [REDACTED]. But nothing was looked at or followed up on. Ms. Haddy suggested I try contacting either the CDC or EPA, I don't recall which one now. But I did contact them both, each one referring me on to the other.

In the Spring of 2018, I'd come into contact with Ginny Davis, EPA in WV who pointed me to Lora Werner who works for the CDC, Agency for Toxic Substances and Disease Registry in Philadelphia, PA, Region 3, Eastern Branch. Ms Werner and I exchanged a few e-mails. At that time, I was still focused on the Roundup and possibly pesticides, the only known exposures at that point. I was looking for someone to do soil sampling to ensure no residual of the pesticide remained so I could feel safe working in the soil and to also obtain help in our area to determine what environmental exposure was causing so much illness, particularly neurological issues in our area. Ms. Werner explained that "sampling was not recommended because they simply do not know what environmental agent to sample for and it was like looking for a needle in a haystack". She went on to explain that the "risk factors for ALS are still largely unknown" and we should enroll with the ALS registry. We had already enrolled with the registry following [REDACTED] diagnosis. I later had the WV Dept of Agriculture sample around our home and found out there was no residual remaining from an exterminator who sprayed outside for ants a few years prior. I sent soil samples from the bank that adjoins our property to a private lab I found online and confirmed glyphosate there. I knew it had been but wanted confirmation. I paid for sampling myself along with mold and radon testing in our home. I have received no help from agencies who are responsible for protecting its citizens. Although I'd previously been concerned about pesticides, as I learned of others affected who lived further from us in the community, I started to think the cause was something different.

In the Spring of 2018 we attended the National ALS Convention in Washington DC. Sara Hoten, Manager of Care Services for ALS in WV knew of my concerns as we'd discussed them several times. She'd had previous contact with our neighbors the [REDACTED] due to [REDACTED] illness with ALS. Prior to the convention, she put me in contact with Kathleen Sheehan, VP of Public Policy with the CDC. She arranged for me to speak with Paul Mehta of the CDC at the convention. After explaining to him about my concerns and desire to have someone visit and research our area, he explained that they cannot come into an area unless invited by the state. So by this time I'd come full circle with everyone pointing me in yet another direction. But nobody was willing to help.

On the day we went up on Capitol Hill to talk to our state's representatives regarding funding for ALS, I always brought up the issue of environmental concerns. When the WV ALS group met with assistants in the offices of Representative David McKinley and Senator Joe Manchin, I relayed my story. Senator Capito met with us last, along with her assistant Dana Richter. I explained that Dr. Mehta of the CDC told me they had to be invited by the state to investigate environmental concerns. Senator Capito had Ms. Richter take my contact information and pledged to look into the matter. They seemed very attentive and understanding of my concerns. I was sure something would finally be done. When I contacted their office a year later for an

update, in May of 2018, I was told that Senator Capito had reached out to the CDC and they were looking into possible next steps. I would like to know what those next steps were/are since nobody had been to our community. Her office later provided me with another phone number of someone else to contact in our state. I made no further contacts at that time. I felt that I had made enough folks aware of our issue already and there were plenty of folks from agencies with resources to help us, agencies whose duty is to act on these matters.

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I continue to work because we need the income and insurance. I'm [redacted] and several years away from Medicare age. Since the summer of 2018, we have had caregivers stay with [redacted] when I work. [redacted]

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[redacted] Ex. 6 Personal Privacy (PP) Nursing Homes are too understaffed to provide the [redacted] Ex. 6 Personal Privacy (PP) he requires. Because [redacted] Ex. 6 Personal Privacy (PP) that would be a scary situation for him. As long as I am able, I will keep him at home. Despite his condition and prognosis, seeing him smile when friends and family come to visit is priceless.

This past Spring, 2019, we were informed that our drinking water was contaminated with tetrachloroethylene, also known as PCE, a chemical used in former dry cleaning businesses in our town. It was found in the wells. Many, many times our water system has been flushed and worked on to try clean it up. Tetrachloroethylene has been known to cause Central Nervous System problems. For our entire lives, we drank unfiltered Paden City water. There was never before any concern. Unsettling though, a newspaper article reports that it was present at least back to 2010 yet we were not informed and continued drinking and bathing in it all those years. According to the WV Code, Chapter 16, when a public water supply is known to be contaminated, the public is to be made aware no later than 30 minutes, not 9 years later. We were assured that the levels reported, while over the EPA guidelines, were still safe. Yet there were times when the readings did exceed the EPA standards. Do you realize that we have only been provided with bottled drinking water two or three times since the contamination was revealed? Residents are buying their own water or consuming the public water. The newspaper reports too that Senator Capito has helped secure funding for remediation of the water system in our town so she is aware of the issue now. My family now drinks and cooks with bottled water but what was consumed prior to the announcement is already in our bodies and I believe there will be continued health related concerns for us and others for many years to come from these exposures. At first I didn't think the water was the problem here but as I have thought and read, it now makes perfect sense. Tetrachloroethylene does not mix with water, it is heavier than water, and therefore would have distributed throughout the lines in an unequal manner and in the cases of some low-lying lines, it is likely still present.

There are many sources of information readily available that state the central nervous system is affected from this chemical. In fact, in "Human Health Effects of Tetrachloroethylene: Key Findings and Scientific Issues", <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3984230/>, you will find the following: "The U.S. EPA's analysis identified the central nervous system, kidney, liver, immune and hematologic systems, and development and reproduction, as target organs of PCE toxicity. (U.S. EPA 2012c)... Neurotoxicity was supported by a considerable database of human, animal, and mechanistic studies. In addition, neurological effects were generally observed at lower PCE concentrations compared with other noncancer health effects. Further, both the 2004 peer consultation workshop (U.S. EPA 2004) and the 2010 NRC peer review (NRC 2010) affirmed the conclusion that neurotoxicity is a sensitive end point because these effects were observed at lower concentrations and had substantial evidential support." Exposure also occurs through skin absorption and we have no choice but to shower and brush our teeth with this water.

For the past three summers, our neighbor Ex. 6 Personal Privacy (PP) widow) and daughter   held ALS walks in our town to try to raise awareness about the disease since the three initial cases were revealed. I later learned of a young man in Morgantown, in his 30s, who can no longer hold his babies because his ALS started in his limbs. His wife's grandmother lives here in the north end of Paden City not far from us. Exposure can occur to non-residents when they visit family and friends and consume water, tea, lemonade and other drinks, and food prepared with the contaminated water. I also learned of another young man in our town recently diagnosed with ALS and two others with Myasthenia Gravis. There have been many, many cases of MS in our town, some very young, many in the north end of town where we reside. We are a small rural town of less than 3000 people. My son-in-law's mother passed away in the summer of 2018 from MS that had only recently been diagnosed. She didn't live far from us. MS, ALS, Myasthenia Gravis, Parkinson's Disease, Fibromyalgia and many other conditions fall under neurological conditions.

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2015 to start  
Now I worry about

what exposures she had while living here. In fact, I worry about all my family and friends who ate and drank anything prepared with our water.

Tetrachloroethylene is reported to cause central nervous system problems among other issues as many reports will tell you. ALS currently has no known causes. I want to see this chemical listed as at least one probable cause of ALS and I want to see stricter testing and lower tolerances adopted and enforced. If nobody can say what causes ALS, then it stands to reason that we cannot say that this does not cause it and we are now sure that our levels caused it. Interestingly, there is a metal factory in southern WV where 8 employees were diagnosed with ALS. One is still living. Because tetrachloroethylene is also used as a metal degreaser, I have to wonder if that is the smoking gun there. Sara Hoten has more information about that factory as she has been in contact with one of the victims. I want to see a community health study conducted here to follow the people in this town, similar to that supposedly conducted as a result of the 2014 chemical spill in Charleston. And I'm not alone. And I want to know why the residents in this town were not told about this in 2010. The WV Code says we are to be notified not more than 30 minutes later when there is contamination. That does not apply solely to spills.

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Our mayor Clyde Hochstrasser was supportive and encouraged us to make some noise.

I sent in samples of my water twice last year to Pace Analytical and twice when time passed and I called about the results, I was told the samples had expired before they were ran. I recently learned that's the same lab that tested for the town. It's my understanding some of those results in some of the crucial periods of time that we're interested in are not available now. I need to look further into that and so do you. This is unacceptable and we deserve some answers. I will be following up with each of you, I will no longer sit back and wait. Our city council meetings are the first Monday of the month at 7:00 am and I invite you all to attend as they are open to the public.

Respectfully,

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CC:

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